

'A' for Adjustment

Session Four - 'A' for Assessment

Guidance, advice and ideas for ensuring a positive, tailored, flexible and effective approach is offered to meet individual needs.

Adjusted Care – an introduction and overview of the Equality Act and the statutory duties including Reasonable Adjustments

Attitude – A framework / opportunity for staff to explore their thinking about disability, learning disability, discrimination and rights.

Approach – Guidance, advice and ideas for ensuring a positive, tailored, flexible and effective approach is offered to meet individual needs

Assessment – A review of the common health problems associated with learning disabilities, what to look out for and tools that can help.

Actions – Guidance for staff on what to do and where to get help in response to individual needs and concerns; includes suggestions on how to improve future responses and follow up actions.

Diagnostic over-shadowing

Diagnostic overshadowing may sound technical and highly clinical but in reality, it simply means making assumptions or jumping to conclusions.

Diagnostic overshadowing occurs when a health professional assumes that a person with learning disabilities' behaviour is a part of their disability without exploring other factors such as biological determinants, for example, the person may be in pain people with learning disabilities may not always display or describe symptoms in a typical, or familiar way.

Diagnostic overshadowing is when the 'diagnosis' of learning disability is wrongly seen as the reason behind any problems, thereby leaving other co-existing conditions undiagnosed. It is particularly likely when new behaviours develop or existing ones increase – issues such as incontinence, self-harm, agitation, tiredness, loss of appetite are all examples of presentations that should never simply be thought of as 'part of a learning disability'.

Given that people with learning disabilities have a much higher risk of experiencing a variety of diseases and conditions, it is vital that physiological or pathological determinants in behaviour change are explored. If they are not, people with learning disabilities can suffer poor care and may even die when their death could be avoided. Just consider one area of likely concern as an example - Gastrointestinal cancers are approximately twice as prevalent in people with a learning disability and approximately 70% of people with a learning disability experience gastrointestinal disorders.

<p>Holistic Care</p>	<p>Holistic care is about inter-dependability - of systems and people, the idea of the whole being greater than the sum of its parts. Holism requires consideration of the many and various internal and external systems and the interactions that constitute health and wellbeing.</p> <p>Caring for and supporting a person holistically is integral to person-centred care (refer to previous modules). Holistic care focuses equally on the physical, psychological, social, cultural, sexuality and spiritual elements of the person. It is a dynamic process of rapport and relationship-building between a clinician and the person with health issues.</p> <p>As such, a broad perspective on physical health is required for communicating effectively with the person and for considering the wider implications of a healthy lifestyle. It can lead to an empowering approach to actions to be taken and for maintaining any behaviour change.</p> <p>Finding out what's important to the person and what they like and value can help practitioners identify activities to support a healthy lifestyle. While holistic care is a useful approach for anyone, adjustments are likely to be required for it to be successful with people with learning disabilities.</p>
<p>Risk factors</p>	<p>Whilst people with learning disabilities experience the same risk factors as anyone else in the population such as ageing, they are also adversely affected by a number of additional factors that have been shown to lead to significant health inequalities; these factors are known as the determinants of health inequalities:</p> <p>There are five key determinants of health inequalities for people with learning disabilities:</p> <ol style="list-style-type: none"> 1. Greater risk of exposure to social determinants of poorer health such as poverty, poor housing, unemployment and social disconnectedness. 2. Increased risk of health problems associated with specific genetic, biological and environmental causes of learning disabilities. 3. Communication difficulties and reduced health literacy. 4. Personal health risks and behaviours such as poor diet and lack of exercise. 5. Deficiencies relating to access to healthcare provision. <p>https://esrc.ukri.org/about-us/50-years-of-esrc/50-achievements/the-dahlgren-whitehead-rainbow/</p>

Awareness of common conditions

Alphabetical list of common health conditions experienced by people with a learning disability (not in order of priority).

Cancer - rates in people with learning disabilities differ from those in people without learning disabilities with higher levels (roughly double) of gastrointestinal cancers such as oesophageal, stomach and gall-bladder, and lower rates of lung, prostate, breast and cervical cancers. Down's syndrome is a risk factor for lymphoblastic leukaemia.

Coronary heart disease - is the second highest cause of death for people with learning disabilities who are more likely to develop hypertension and obesity, and lack exercise, all of which are risk factors for ischaemic heart disease. People with Down's syndrome are at higher risk of congenital heart problems.

Dental issues/oral hygiene - People with learning disabilities are more likely to have tooth decay, loose teeth, gum disease, higher levels of untreated disease, and a larger number of extractions. This may be explained by a poor diet, poor dental hygiene and because oral health promotion may not be accessible to people with learning disabilities. Despite this they are less likely to visit their dentist.

Diabetes – higher rates attributed to increased levels of obesity, poor diet and inactive lifestyles.

Epilepsy - is more prevalent in people with learning disabilities (35%). The prevalence rises with an increase in severity of learning disabilities, with nearly half of people with severe learning disabilities having epilepsy. People with learning disabilities who have epilepsy often have more than one type of seizure and more complex seizure patterns. They are at risk of further cognitive impairment due to prolonged seizures, secondary injuries that might go unnoticed, hospitalisation, placement breakdown, a more restricted lifestyle, and unexpected death. Where more than one medication is used potential side effects, such as sedation and constipation, need to be considered.

Gastro-intestinal problems - Many people with learning disabilities have high levels of helicobacter pylori which is associated with peptic ulcers. Gastro oesophageal reflux disease (GORD) can affect as many as half of people with learning disabilities, and has a higher prevalence in those with more severe and profound learning disabilities. Constipation is more prevalent and is more likely to occur in people with profound learning disabilities, those who are less mobile, where there is inadequate hydration or limited food choice, and in people on long-term medication with constipation as a side effect. People with Down's syndrome are prone to coeliac disease.

Mental health problems - Common mental health problems include: Anxiety disorders, phobias and panic disorders. Anxiety is often seen in people with autistic spectrum conditions, especially when their routine and structure is disrupted. Depression can be difficult to diagnose when there are communication difficulties, where physical signs such as weight loss, a change in sleep pattern, or social

withdrawal might suggest depression along with atypical indicators such as self-injury or aggression, uncharacteristic incontinence or screaming. Schizophrenia is three times more prevalent in people with learning disabilities.

Obesity - Levels are higher in people with learning disabilities and are more notable in those with milder learning disabilities, especially women. Obesity can have secondary effects on health and increase the likelihood of heart disease, stroke and Type II diabetes. People with learning disabilities are less likely to have a balanced diet, are less likely to take regular physical exercise, may have trouble understanding health promotion material, may live in restrictive environments, may be on medications that have weight gain effects. Some genetic conditions are associated with obesity, including Down's syndrome and Prader-Willi Syndrome. Some people with learning disabilities are at risk of being underweight. This is seen more in people with more profound learning disabilities or in those with metabolic disorders such as phenylketonuria.

Respiratory disease - the main cause of death in people with learning disabilities. They are at risk of respiratory tract infections caused by aspiration or reflux if they have swallowing difficulties, and they are less likely to be immunised against infections. People with Down's syndrome are particularly at risk because they have a predisposition to lung abnormalities, a poor immune system and a tendency to breathe through their mouth.

Sensory impairments - Sight and hearing problems are common in people with learning disabilities; it is estimated that up to 40 percent of people with learning disabilities have sight problems and a similar number of people with severe learning disabilities have hearing problems. People with learning disabilities are more prone to ear and eye infections. People with learning disabilities have a higher prevalence of sight problems. Sight problems may be acquired as people get older. Some causes of learning disabilities, such as Down's syndrome, cerebral palsy, fragile-X syndrome and foetal rubella syndrome, are associated with vision problems. People with learning disabilities are more likely to need a hearing aid, but many have never had a hearing test. Hearing problems might further compound already poor communication skills; impacted earwax has a higher prevalence in people with learning disabilities. Some diagnoses, including Down's syndrome, foetal rubella syndrome, cerebral palsy and fragile X syndrome, are particularly associated with hearing loss.

Swallowing problems - are more prevalent with the highest prevalence in those with profound disabilities which can be caused by neurological problems or structural abnormalities of the mouth and throat. Problems can also arise from rumination, regurgitation or self-induced vomiting. Swallowing problems can lead to choking, secondary infections and weight loss.

	<p>Thyroid disease – hypothyroidism is more common in people with learning disabilities and is associated with Down’s syndrome; symptoms include weight gain, constipation, aches, feeling cold, fluid retention, tiredness, lethargy, mental slowing and depression.</p> <p>Further learning resources The A –Z OF health issues affecting people with a learning disability - NHS.uk/A -Z of Health Issues</p> <p>Go to Minded - Supporting People with Learning Disability, Health/Mental Health Problems and Transitions - This Minded e-learning module considers the support and care of children, young people and adults with a learning disability, including people with autism and learning disability. It covers epilepsy, physical health care, transitions from youth to adult mental health care, and for children and young people it covers psychosis, bipolar and mood disorders.</p> <p>Health issues and autistic people</p> <p>One in a hundred people in the UK has autism, a lifelong developmental disability that affects how a person communicates with, and relates to, other people. Some autistic people are able to live independent lives but many have learning disabilities or co-occurring healthcare conditions, often requiring a lifetime of specialist support, as well as the health issues we all face as part of the normal ageing process.</p> <p>Many families and autistic individuals have raised concerns over early deaths in autistic people. Research studies have confirmed that autistic people die on average 16 years earlier than the general population. There are specific social, cultural and sensory challenges for autistic people which can contribute to premature mortality.</p> <p>Two leading causes of early death in autism are epilepsy and suicide. Research shows that autistic people are at heightened risk of mental health problems such as depression and anxiety, neurological conditions, especially epilepsy, and other diseases including diabetes and heart disease.</p> <p>Read more at www.autistica.org.uk/personal tragedies public crisis</p>
<p>Symptom recognition</p>	<p>People with a learning disability often rely on others to spot the signs that they are unwell. Some people die because those caring for them have not noticed or reacted quickly enough to a change in the person’s health. Many people with a learning disability and/or autism take multiple medications with side effects that can go unrecognised.</p> <p>Whilst signs of potential deteriorating health are no different for people with learning disabilities to other people, they can sometimes be missed due to Diagnostic Overshadowing or they may present slightly differently.</p>

STOMP-STAMP Pledge

Tools to help

Always look out for and enquire about:

- Changes in consciousness/awareness – including subtle changes such as increased anxiety, confusion or restlessness
- Changes in heart and circulation – changes in heart/pulse rate, dizziness, feeling faint, chest pain, sweating. High (above 37.50C) or low (35.0C or below) body temperature, chills or shivering
- Changes in breathing – breaths sound different to usual, using effort to breathe, nostrils flaring when breathing, cough
- Changes in skin colour – mottling of skin, rash, pallor, blueish tinge to lips
- Changes in bowels – diarrhoea or vomiting, distended abdomen
- Changes in urine output –, change in quantity, colour or smell of urine (measure urine or weigh pads to check)
- Other changes eg. pain, person not feeling well, change in appearance or behaviour including medication and potential side effects

STOMP-STAMP (Stopping over medication of people with a learning disability, autism or both-Supporting Treatment and Appropriate Medication in Paediatrics) pledge resources for organisations and individuals that work with children and young people with a learning disability, autism or both to show their commitment to stopping over medication. Find out more and download resources here:

www.england.nhs.uk/publication/stomp-stamp-pledge-resources

Tools to help

The PINCH ME mnemonic was developed for assessing delirium in older patients but is increasingly being acknowledged as a helpful framework for understanding what may be underlying problems for people with learning disability:

- * **P**ain
- * **I**Nfection
- * **C**onstipation
- * **H**ydration
- * **M**edication
- * **E**nvironmental

Think **PINCH ME!**

SBAR - [Brief guide to SBAR - NHS England](#)

SBAR is an easy to use, structured form of communication that enables information to be transferred accurately between individuals.

	<p>SBAR can be used in any setting but can be particularly effective in reducing the barrier to effective communication across different disciplines and between different levels of staff.</p> <p>Carers and families offer an invaluable source of information to help in assessing, listen to the concerns of others who know the person well, and act on these.</p> <p>The SBAR mnemonic provides a useful structure to encourage carers to share information:</p> <p>Situation –who they are, who the person is, signs and symptoms, what their concerns are</p> <p>Background – how long the person has been ill, when their condition changed</p> <p>Assessment – what they think the problem is</p> <p>Recommendation – what they want to happen</p> <p>Other tools to help</p> <p>There are a range of resources available to help in the recognition of deteriorating health, the Stop and Watch project is a good example:</p> <p>https://northcumbriaccg.nhs.uk/your-health/campaigns/stop-and-watch-resources</p> <p>The Learning Disability Mortality Review team at Bristol University have produced useful posters that focus on known common conditions associated with premature mortality including: Sepsis, Constipation and Aspiration Pneumonia</p> <p>https://www.bristol.ac.uk/sps/leder/resources/information-and-resources-for-social-care-providers/</p> <p>The Learning Disability Public Health Observatory have produced a range of Reasonable Adjustment guides on different conditions:</p> <p>https://www.gov.uk/government/collections/reasonable-adjustments-for-people-with-a-learning-disability</p> <p>Go to : www.skillsforcare.org.uk/autism for autism awareness learning resources that have been developed by a range of organisations to increase awareness and understanding of autism including the 'Skills for Care video - tell it like it is' – a short video about important things to remember when doing any type of assessment for someone with autism.</p>
<p>Pain management</p>	<p>It can be hard to recognise if some people with a learning disability are in pain. People may not say they are in pain and may not act in a way that you would expect people in pain to act, particularly if they do not communicate verbally.</p>

People who have health needs, especially those who are immobile or wheelchair dependent, are likely to suffer from long-term pain.

Sometimes when people are in pain, they may display challenging behaviour –this might include trying to hurt themselves or others. Other people may become quiet or withdrawn or they may show unusual behaviours like laughing or crying. This sort of change in behaviour should not just be assumed to be because they have a learning disability. They might be showing that they are in pain.

Many people with a learning disability will not ask for medication for their pain. Some people believe that people with a learning disability can tolerate more pain than the general population. This is not true.

People with learning disabilities, like non-disabled people, will have individual and different responses to pain.

Signs and symptoms that a person may be in pain include:

- aggression directed towards themselves or others;
- changes to how the person holds or moves their body, including altered facial expression;
- changes to mobility or balance;
- change in behaviour, such as tearfulness, irritability or withdrawal;
- changes to appetite or vocalisation;
- confusion;
- restlessness or changes in sleep patterns.

There are a range of tools available to help identify when someone with a learning disability may be in pain including the Disability Distress Tool (Dis – Dat) see:

<https://www.choiceforum.org/docs/asst.pdf>

Unique wellness/ unwellness

You will have seen from the sections above that the key to a good assessment is a good understanding of the person. By understanding how the person is usually you can then begin to think about what is different now and what might be causing that difference:

What is normal? - What has changed?

Changes that may indicate an underlying problem may well be different for someone with a learning disability or autism, this is the concept of 'Unique unwellness'.

An example may be that a person with a severe learning disability and physical disability may have a blood pressure that is below the 'normal' range but is 'normal' for them – if you do not know this, or find out, then when you take their blood pressure and it is raised (for them) you may assume their blood pressure is not a problem as it is still within what you ordinarily think of as a 'normal' range.

This concept and understanding applies to other signs and measures too such as temperature. Work is underway to utilise the National Early Warning Signs (NEWS 2) in a way that ensures deterioration in health for patients with learning disabilities can be effectively detected

<https://www.weahsn.net/our-work/improving-patient-safety/the-deteriorating-patient/news/>

Take Action - Assessment

What will be different?

What will you do differently as a result of your learning today?

How will you take action?

Who will you involve? Do you require any additional learning or support and where would you go to access this?

By when will you do this?


Health Education England



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